

Palliative Care Matters for All Respondent Information Form

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Are you responding as an individual or an organisation?

- ☐ Individual
- ☒ Organisation

Full name or organisation's name

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The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

- ☒ Publish response with name
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Information for organisations:

The option 'Publish response only (without name)' is available for individual respondents only. If this option is selected, the organisation name will still be published.

If you choose the option 'Do not publish response', your organisation name may still be listed as having responded to the consultation in, for example, the analysis report.

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

- ☒ Yes
- ☐ No

Section A: Overall Strategy

Question 1a. Do you agree with the aims for this strategy?

The aims of the strategy are that, by 2030:

- adults and children in Scotland have more equitable access to well-coordinated, timely and high-quality palliative care, care around dying and bereavement support based on what matters to them, including support for families and carers.
- Scotland is a place where people, families and communities can support each other, take action and talk more openly about planning ahead, serious illnesses or health conditions, dying and bereavement
- adults and children have opportunities to plan for future changes in their life, health and care with their families and carers.

[Please only mark **one** box below]

- ☒ Agree
☐ Disagree
☐ Unsure / Don't know

Question 1b: Please add any comments you have about the strategy aims here:

Question 2a. Do you agree with the strategy cornerstones, which form the basis for the strategy and delivery plans?

We used four 'cornerstones' as the foundations for change and improvements in palliative care policy, service delivery and public involvement. These are:

- Working together to provide the care that's right for each adult or child, their family and carers.
- Taking a whole-system population health approach using data and people's experiences
- Ensuring equity and equality of access to palliative care for anyone who needs it
- Leadership across health and social care systems and with wider delivery partners, including third sector organisations (charities)

[Please only mark **one** box below]

- ☒ Agree
☐ Disagree
☐ Unsure / Don't know

Question 2b: Please add any comments you have about the four strategy

cornerstones here:

Section B: Strategy outcomes

Question 3a. Do you agree with strategy outcome 1 and the proposed actions being developed to deliver this outcome?

Outcome 1: People have the understanding, information, skills and confidence to support themselves and others to live well with serious illnesses or health conditions; to plan for the future; and to support each other through dying and bereavement.

Proposed actions:

- Take forward work across relevant policy areas to improve the wider experiences of people receiving palliative care and care around dying; remove barriers to access; and maximise support, including areas related to children and young people, equalities, justice, fair work, housing and tackling poverty.
- Explore ways to promote access to financial benefits for adults or children with serious illnesses or health conditions and increasing health and care needs under the Benefits Assessment for Special Rules in Scotland (BASRiS) application process through improved public information and professional education and guidance.
- Work with agencies, statutory and third sector organisations responsible for housing and services for people who are homeless or vulnerably housed to develop and promote ways to enable adults and children living with serious illnesses or health conditions to access the social, practical and financial assessments and support they need.
- Collaborate with NHS 24 and wider partners to make sure the NHS inform website provides relevant, up to date and accessible public information about future care planning, palliative care and care around dying for adults and children, families and carers, including links to support organisations and resources for people from diverse groups and communities.
- Support the Scottish Partnership for Palliative Care (SPPC) to provide a sustainable, national infrastructure that enables statutory and third sector

organisations, palliative care providers, staff, community groups and individuals to work together to promote understanding and awareness of living and dying with serious or life-threatening illnesses and serious health conditions; and to contribute towards empowering people to be more informed and equipped to plan ahead and support each other through serious illness, dying, death and bereavement.

- In partnership with the third sector, widen access to community-led public education opportunities which provide knowledge, skills, resources and training to help more people be comfortable and confident in supporting family, friends and people in their local community when someone is dying, caring or bereaved.
- Work with Integrated Joint Boards (IJBs) and Health and Social Care Partnerships (HSCPs) to explore options for their strategic plans for palliative care to recognise and work collaboratively with local community groups, networks and projects that offer support for adults with serious illnesses; children and young people with serious health conditions; and their families and carers.

[Please only mark **one** box below]

- ☒ Agree
☐ Disagree
☐ Unsure / Don't know

Question 3b: Please add any comments you have about outcome 1 and its actions

here:

Question 4a. Do you agree with strategy outcome 2 and the proposed actions being developed to deliver this outcome?

Outcome 2: Leaders, stakeholders and delivery partners will work together in partnership, with clear roles and responsibilities, to make sure there is reliable and effective planning, delivery, accountability and improvement of palliative care services and wider support.

Proposed actions:

- Develop guidance with IJBs and Health Boards to support the identification of a clinical and a managerial / executive lead, and to establish a Managed Care Network (MCN), updating previous guidance for Health Boards on MCNs.

- Work with Health Boards to establish new requirements for inclusion of integrated specialist palliative care services within annual delivery plans and performance monitoring.
- Work with HSCPs and adult independent hospice organisations to develop a national guidance framework to support and improve consistency of local planning and commissioning of independent hospice services.
- Work with the Scottish Partnership for Palliative Care to establish a national Palliative Care Innovation Network, where people and teams involved in palliative care delivery; community-led initiatives; improvement and research; or education can come together to share learning and ideas for improvement and innovation.
- Continue to engage with palliative care delivery partners on how the proposed National Care Service Board and the reformed Integration Authorities will improve national and local governance, roles, responsibility, commissioning, monitoring and reporting of specialist palliative care services and general palliative care

[Please only mark **one** box below]

- ☒ Agree
☐ Disagree
☐ Unsure / Don't know

question 4b: Please add any comments you have about outcome 2 and its actions here:

Question 5a. Do you agree with strategy outcome 3 and the proposed actions being developed to deliver this outcome?

Outcome 3: National and local leaders will have access to relevant data to inform planning and delivery of services; and will put in place improved ways to monitor and evaluate the outcomes and experiences of children and adults receiving palliative care, as well as their families and carers.

Proposed actions:

- Work with Public Health Scotland, Health Boards, HSCPs, and other key partners, including paediatric palliative care planners and service providers, across all sectors to improve the quality and range of palliative care data collected, analysed and reported. Such data can be used to inform

improvement, experiences, and delivery of palliative care for adults and children, families and carers, and includes:

- updating and improving the existing adult palliative care population data reporting systems; and providing access for service planners and health and care staff.
 - developing a national approach to data collection on paediatric palliative care services for babies, children and young people (0 -18 years) and developing a new dashboard that can be accessed by paediatric palliative care service planners, and health and care staff.
 - working with HSCPs and Health Boards to develop a data template that supports them to collect, analyse and report high quality data on general palliative care and specialist palliative care services delivered to adults, children and young people for service planning and improvement, which includes user experiences in all places of care.
 - development of a Scottish minimum data set for all adult specialist palliative care services.
 - development of a Scottish minimum data set for all paediatric and neonatal specialist palliative care services and transitions.
- Explore evidence based and emerging co-design approaches to hearing and measuring people's experiences of palliative care, care around dying and bereavement support in palliative care for all places of care, and establish a consistent national approach to help improve these experiences.

[Please only mark **one** box below]

- ☒ Agree
☐ Disagree
☐ Unsure / Don't know

question 5b: Please add any comments you have about outcome 3 and its actions here:

We very much welcome the plans to develop a Scottish minimum data set for all adult specialist palliative care services. This would enable better planning of services to meet local needs, facilitate greater integration and support both providers and central bodies to compare information and better understand the national picture.

Question 6a. Do you agree with strategy outcome 4 and the proposed actions being developed to deliver this outcome?

Outcome 4: Adults with serious or life-threatening illnesses will be identified earlier and be able to access general palliative care and specialist palliative care services, whenever and wherever needed.

Proposed actions:

- Work with Healthcare Improvement Scotland (HIS) to improve guidance and promote improvements in use of evidence-based tools to support proactive identification and review of adults with unmet palliative care needs, their families and carers, by staff and teams working across health and social care in all HSCPs and Health Boards.
- Work with NHS National Services Scotland (NSS) and HIS and digital science experts to explore further development and implementation of national health records screening tools to improve identification of adults with serious or life-threatening illnesses for earlier palliative care and future care planning.
- Explore viable options with NHS 24 and other delivery partners to provide a 24/7 national palliative care advice line (via the 111 system) for patients, families and carers that reduces delays in access to urgent primary care and social care and connects with locally delivered palliative care telephone helplines and services.
- Support collaborative working to promote inclusion of palliative care and care around dying in service planning and delivery for people with one or more long term health conditions.
- Support innovative models of care and consider options for service developments and partnership working to increase equity of access to adult specialist palliative care both in-hours and out-of-hours in all Health Boards and HSCPs, including a specific focus on people who have more barriers to accessing the specialist palliative care they need.
- Explore options with Health Boards and HSCPs to make sure there is consistent access at all times (24/7) to specialist clinical care from a consultant in palliative medicine and from senior nurse specialists whenever a person is receiving inpatient hospital or community hospital specialist palliative care, including contractual arrangements to support rural and island Health Boards.
- Work with Health Boards, HSCPs and third sector organisations to improve access to urgent palliative care services in the community that can reduce avoidable hospital admissions and shorten inpatient stays, and provide more effective, timely admission processes for those needing hospital care. This includes improving access to specialist palliative care advice in hospital and at home within wider national and local work on unscheduled care and early hospital discharge.

- Work with Health Boards, HSCPs and third sector organisations to support improved provision of professional-to-professional specialist palliative care clinical advice lines, ensuring these are available 24/7 in all parts of Scotland, so that other health and care staff providing palliative care, including the Scottish Ambulance Service, can access specialist palliative care advice at all times.
- Work with Health Boards, HSCPs, third sector organisations, other delivery partners, and community groups to improve palliative care, care around dying and bereavement support for people from minority communities and other groups who face barriers to accessing palliative care or who need flexible approaches tailored to their health conditions, situation, personal circumstances, values and preferences.

[Please only mark **one** box below]

- ☒ Agree
☐ Disagree
☐ Unsure / Don't know

question 6b: Please add any comments you have about outcome 4 and its actions here:

Question 7a. Do you agree with strategy outcome 5 and the proposed actions being developed to deliver this outcome?

Outcome 5: Adults living with serious or life-threatening illnesses and children with serious health conditions will be offered person-centred future care planning involving their families and carers, and care plans will be recorded and shared using national digital systems.

Proposed actions:

- Support a national partnership programme for future care planning, overseen by the National Future Care Planning Working Group, that is person-centred, inclusive and takes a 'Once for Scotland' and 'digital' approach to development and delivery for children, young people and adults whose life, health or care may change, and which is suitable for all places of care.
- Continue to work with NHS Education for Scotland (NES) Digital, other national organisations and partners to develop and implement a national electronic urgent and emergency care plan for health and social care accessible to staff working in the community, NHS unscheduled care services and hospitals in all Health Boards, starting with health care staff and extending to social care staff, care homes and independent hospices.

- Continue to work with NES Digital, other national organisations and partners to develop and implement a national electronic hospital urgent care plan to improve treatment and care during a single hospital admission that connects digitally with community urgent and emergency care plans.
- Continue to work with NHS Education for Scotland, other national organisations and partners to develop and deliver national education and implementation resources on future care planning for use across Scotland.
- Promote future care planning across all sectors and involve a wide range of stakeholders in development and delivery including members of the public, adults, young people, families, parents and carers, minority groups, patient support groups and third sector organisations, and to develop accessible and inclusive resources and information about future care planning with them.

[Please only mark **one** box below]

- ☒ Agree
☐ Disagree
☐ Unsure / Don't know

question 7b: Please add any comments you have about outcome 5 and its actions here:

Question 8a. Do you agree with strategy outcome 6 and the proposed actions being developed to deliver this outcome?

Outcome 6: Quality and experiences of care around dying and bereavement support are improved for adults, their families and carers, in all places of care.

Proposed actions:

- Oversee an update to the national guidance on *Care around Death* and work with Health Boards and HSCPs to make sure it is implemented as best practice in all places of care in Scotland.
- Work with Health Boards , HSCPs, primary care teams and pharmacy services to promote timely provision and use of 'just in case medicines' for adults dying at home and residents in care homes and improve staff education and public information.
- Work with HSCPs and Health Boards to promote and develop effective models of urgent palliative care able to provide rapid access to coordinated

health and social care support for adults dying at home, their families and carers.

- Work with Scottish Ambulance Service and NHS Education for Scotland to ensure palliative care continues to be part of core training and professional development for ambulance clinicians.
- Oversee an update the public information leaflet “*When someone has died – information for you*” with NHS Education for Scotland and other partners, and promote its use along with additional local information through Health Board Bereavement Leads, HSCPs, and other organisations, including NHS Inform.
- Continue to champion, co-ordinate and work in partnership with key stakeholders to ensure compassionate advice, resources and support are available for people experiencing bereavement, following the death of an adult with a serious or life-threatening illnesses, or with a child who has a serious health condition, and explore improvements to bereavement care.
- Work with NHS Education for Scotland and other partners to develop a new education and training resource on bereavement care for staff across health and social care that includes staff support and spiritual care as part of the [Support Around Death](#) resources.

[Please only mark **one** box below]

- ☒ Agree
☐ Disagree
☐ Unsure / Don't know

question 8b: Please add any comments you have about outcome 6 and its actions here:

Question 9a. Do you agree with strategy outcome 7 and the proposed actions being developed to deliver this outcome?

Outcome 7: Babies, children and young people living with serious health conditions, and their families and carers, will experience improved support as their distinctive needs are recognised and addressed by paediatric palliative care, including care around dying or as they transition into adult services.

Proposed actions:

- Work with key partners to develop a national approach to service planning for all paediatric palliative care, through a multi-agency steering group, to ensure children and families across Scotland have access to the services they need,

wherever and whenever these are required, and to ensure that these services are equitable.

- Work with CHAS and Health Boards to review current models and develop a national specialist paediatric palliative care service available at all times (24/7) to meet the needs of children, families and staff across Scotland in all places of care.
- Support and develop improved transitions for young people with serious health conditions based on Getting It Right For Everyone (GIRFE) practice model, and the co-designed GIRFE 'team around the person' toolkit for young people in transition from GIRFEC (Getting it Right for Every Child) to GIRFE.
- Draw on best practice models to develop and agree paediatric palliative care standards to children and families across Scotland have equitable access to high quality general and specialist paediatric palliative care services wherever and whenever these are required.
- Explore options for a national approach to providing ethical clinical review of decision making in paediatric palliative care.

[Please only mark **one** box below]

- ☐ Agree
☐ Disagree
☒ Unsure / Don't know

question 9b: Please add any comments you have about outcome 7 and its actions here:

We do not feel best placed to comment on this outcome as Sue Ryder provides palliative and end-of-life care to adults only.

Question 10a. Do you agree with strategy outcome 8 and the proposed actions being developed to deliver this outcome?

Outcome 8: Employers, professional bodies and education providers will make sure that staff who deliver palliative care are trained, skilled and supported.

Proposed actions:

- Work with Healthcare Improvement Scotland (HIS) to ensure there is sustainable management, updating and extension of the Scottish Palliative Care Guidelines as recommended best practice for symptom management across Scotland on the Right Decision Service; and explore options to develop and include Scottish paediatric palliative care guidelines.
- Work with NHS Education Scotland (NES) to develop a designated online learning space readily available to all health and social care staff who deliver

palliative care to adults, children and young people that provides a single point of access to relevant training and education resources on palliative care, care around dying and bereavement support.

- Work with NHS Education for Scotland (NES), statutory and third sector organisations, and education providers to support and enable local and national education and training for health and care staff to equip them to have sensitive and effective person-centred conversations with adults or children, families and carers, that are central to future care planning, palliative care, and care around dying, including NES [Having Realistic Conversations](#) resources.
- Work with NHS Education for Scotland (NES) and third sector palliative care education providers to promote and develop online learning opportunities and networks for health and social care staff across Scotland such as Project ECHO.
- Work with universities and further education colleges that provide pre-registration courses and undergraduate education programmes to enable all health and social care staff (including doctors, nurses, pharmacists, allied health care professionals and social workers) and to receive a level of adult or paediatric palliative care education appropriate to their roles.
- Encourage HSCEPs and Health Boards to employ palliative care practice educators to support the sustainable delivery of palliative care education and training in line with the NES/SSSC Palliative Care Education Framework and work collaboratively with adult and paediatric palliative care specialists offering education and training.

[Please only mark **one** box below]

- ☒ Agree
☐ Disagree
☐ Unsure / Don't know

question 10b: Please add any comments you have about outcome 8 and its actions here:

We agree that it is important there is a sufficiently trained palliative care workforce, but it is also needs to be ensured there are enough staff to deliver the proposals within this strategy.

Hospices recruit from the same pool as the NHS and so are impacted by the widespread healthcare workforce shortages. To help to overcome this, planning for the workforce requirements of the health and social care system must include the palliative care workforce. This will help to prevent unintended consequences for vital services that sit outside of the core NHS structure but are a critical part of a functioning healthcare system.

Question 11. Please add any further comments you have about the draft strategy outcomes and actions here.

Question 12a. Community action and support - Do you think this strategy explains why it is important to encourage people, families and communities to come together, support each other, take action and talk more openly?

Living well with serious illnesses and health conditions, dying and loss are universal experiences affecting everyone.

- ☒ Yes
☐ No
☐ Unsure / Don't know

Question 12b: Please add any comments you have about how to do this better in Scotland.

Question 13a. Earlier access to palliative care - Do you think this strategy explains why getting palliative care long before someone is dying can help adults, children, their families and carers?

Many people don't understand that palliative care helps adults with serious illnesses or children with serious health conditions to live as well as possible. Some people think they can only get palliative care in the last weeks or days of life. In fact, some adults and children can benefit from palliative care over many years.

- ☒ Yes
- ☐ No
- ☐ Unsure / Don't know

Question 13b: Please add any comments you have about earlier access to palliative care here.

Question 14a. Improving access to palliative care and support - Do you think that the actions in this strategy can improve the experiences of people with different personal characteristics and circumstances?

How adults and children, their families and carers experience living and dying with different illnesses; access health and care services; and use their own community support networks is affected by their health conditions, situation, location, culture and personal circumstances. These include:

- age
- disability
- race or ethnic group
- religion or belief
- gender
- sex
- sexual orientation
- rural or island areas
- socio-economic deprivation (poverty)
- illnesses or health conditions

- ☒ Yes
- ☐ No
- ☐ Unsure / Don't know

Question 14b: Please add any comments you have about impacts of the strategy on these or other groups of people here.

Question 15a. Language and terms used in the strategy - Do you think the strategy explains what is meant by the terms palliative care for adults; palliative care for children; care around dying; and future care planning?

It is important to use consistent terms and language that everyone can understand.

- Care around dying - care around dying means whole person care for an adult or child who is dying and in the last hours, days or weeks of their life, care after their death, and support with loss and grief for families and carers throughout this time and when they are bereaved.
- Future care planning - future care planning means supporting adults and children, their families and carers, to think and plan ahead for changes in their life, care or health.
- Palliative care for adults - palliative care is holistic care that prevents and relieves suffering through the early identification, assessment and management of pain and other problems – whether physical, mental health, social or spiritual.
- Palliative care for children and young people - palliative care for children and young people is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life. It includes physical, emotional, social, and spiritual elements, and focuses on enhanced quality of life for the child or young person and support for their family.

☒ Yes

☐ No

☐ Unsure / Don't know

Question 15b: Please add any further comments you have about any of the terms that are used in the draft strategy.

Question 16. Please add any other comments or suggestions you have about the draft Palliative Care Strategy here:

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